



A FOUNDATION BUILDING STRENGTH

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A FOUNDATION BUILDING STRENGTH AWARDS \$748,000 IN RESEARCH GRANTS FOR NEMALINE MYOPATHY

Much-Needed Research Continues, Even in Challenging Times

PALO ALTO, CA – October 9, 2020. A Foundation Building Strength, an independent 501c3 founded to advance research for Nemaline Myopathy (NM), is pleased to announce the recipients of its “Stronger 2020” grant call. The current five grants total nearly three-quarters of a million dollars, reflecting the organization’s ongoing commitment to advancing research for the ultra-rare NM, no matter the circumstances.

A Foundation Building Strength (AFBS) is largely volunteer-run, composed of a Board of Directors who are parents of affected children, who hail from the biotech industry, and who contribute their time and talents to advancing research of NM, a genetic, ultra-rare, as-yet-incurable disease. Since its founding in 2008, the organization has independently supported more than \$2.6 million in research, funding projects that have built the foundation for research in NM and moved the needle toward treatments and a cure.

A total of five grants have been awarded to projects that range from basic understanding of pathology mechanisms, to gene therapy, to efficacy-testing of existing compounds. Targeted material includes the ACTA1 and Nebulin genes but also gene- and mutation-agnostic interventions, like gene modifiers modulation, trying to achieve potential therapeutic interventions to the wider spectrum of NM.

“The proposals we received this year were varied, innovative, with voices that AFBS hadn’t heard from in the past,” says the Scientific Director of AFBS, Dr. Gustavo Dziejczapolski. “The growing interest in NM research and the expanding community signals an even brighter future for discoveries in this disease area.”

Marc Guillet, founder and Executive Director of AFBS, stresses the organization’s commitment to research. “COVID19 has created an uncertain climate for many of us. But the AFBS Board of Directors discussed how to handle difficult times -- and we all agreed that continuing research is perhaps even a higher priority than ever. The challenges our community experiences don’t stop because of a pandemic.”

(more...)

Guillet continues, “Our community has demonstrated their commitment to us by donating their time and resources to AFBS. It’s our job to be more responsive than ever, and push forward the research that leads to our ultimate goals to find treatments and a cure.”

Learn more at www.buildingstrength.org.

A Foundation Building Strength

A Foundation Building Strength (AFBS) is a global organization founded in 2008 to provide family support and advance research of Nemaline Myopathy (NM), a genetic disorder that causes severe muscle weakness, robbing children of the ability to breathe, swallow,, and play like other kids their age. AFBS is the only independent nonprofit organization focused solely on advocacy and research for NM, working on behalf of thousands of children and adults who live with disease around the world. In just over a decade, AFBS has connected the affected, clinical, and research communities, increased awareness of the disease, created the first-ever Congenital Myopathy Care Guide, funded more than \$2.5 million in NM research, and created a foundation for long-term support and more importantly: hope for those affected.

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